PREFACE

An increasing number of scholars are now pursuing community-engaged research and collaborating closely with community members who actively participate in the research process. Although these research approaches are gaining momentum, there is a dearth of resources that focus on the nuts and bolts of community-engaged research to guide teams interested in this work, particularly with research involving marginalized communities. Our research team started working on a community-engaged research project in 2019 with people living and working in prison. After we started the project, our community partners (i.e., prison staff and incarcerated people) shared that they did not have enough knowledge of research to authentically engage in the research process with us. Our team searched for texts that would be helpful teaching aids for people new to research or with some foundational knowledge of traditional research, but few accessible resources were available. Through this journey, our team developed this book and the companion resources.

We use a social justice and empowerment perspective in this text to emphasize the importance of utilizing alternative and transformative research approaches over traditional models. Our goal is to highlight collaborative models in which the community is centered and an integral part of the study instead of being treated as merely the subject of the work. Community-engaged research approaches, when done well, have the potential to improve research translation to community stakeholders and to increase the benefits of research to communities. Community-engaged research approaches can be especially impactful when collaborating with vulnerable and marginalized populations who, historically, experience more harm than good from research. We highlight how community-engaged research can address power imbalances and empower community members to be active partners in the research process. We highlight the dark history of research that has harmed communities of color and people living in poverty to advance science. We acknowledge this history in our text and spell out how community-engaged research approaches can work to heal past harms and build mutual trust as all parties work collaboratively on shared interests.

Our mission in authoring this book was to create a concise, accessible, and applied *how-to* guide for people interested in conducting community-engaged research. We define specific community-engaged research approaches and couple them with strategies, resources, and tips offered throughout the book in the context of social justice and ethics. Conducting community-engaged research, particularly with marginalized populations, requires a specific skill set and strategies to ensure ethical and just practice. Two authors are social workers and two are social justice-oriented criminologists. Our professional values include using person-first language, recognizing gender fluidity, acknowledging the impacts of systemic racism, addressing social determinants of health, and creating inclusive environments. These professional values are the foundation of this book, and the cases described within the book. We are all university-based,

tenured professors, two of whom are newly tenured. We regularly co-write research briefs and peer-reviewed articles with our community research partners. However, writing this book with one or many of our community research partners was not possible. Our job provides us with time and space to write this book, which is far more time-consuming than a single article. Our community partners do not have this same opportunity in their jobs. Community partner voices are present in this book, though, with quotes from them about their experiences and advice for academic and community researchers.

USING THE TEXT

This book is specifically intended to build capacity for people to utilize community-engaged research approaches ethically and proficiently. The text is divided into three parts to provide readers with the knowledge, skills, and strategies needed to carry out community-engaged research with marginalized populations. This text is not meant to be a detailed handbook for participatory research—as there are many excellent resources available. Part 1 defines the continuum of community-engaged approaches, examines the origin of the approaches, and positions these approaches as one strategy to respond to historical traumas that researchers have caused for marginalized populations. Part 2 outlines the "nuts and bolts" of community-engaged research, from building connections with communities to the co-creation of research projects. We discuss how to establish and build trust, build capacity for community members to engage in the research process, and conduct community-engaged research using rigorous research methods. We offer a companion **booklet**[1] as a tool to build bidirectional capacity for community and academic research partners to work alongside each other. It is an easy-to-read introduction to research for persons who have no formal training in research and provides suggestions for community trainings for academic researchers who are unfamiliar with their partnering community. Finally, Part 3 details strategies for inclusive research practices of balancing voices, addressing ruptures in relationships, sharing findings, and planning for sustainability.

We use myriad pedagogical techniques in the text. The text uses easy-to-read narratives coupled with visuals, call-out boxes, and photos of the narrative content "in action" to stimulate visual learners. Authors have all taught research methods and currently conduct community-engaged research; our experiences are infused throughout the book and supplemental materials. Our team has extensive experience using these research approaches in health, mental health, and criminal-legal research. We use these experiences as case studies and examples to bring the book to life. We also utilize case studies from a range of other projects including examples from urban planning, public health, and natural sciences to name a few, making the text widely inclusive of various disciplines. Each chapter of the text includes three to five learning objectives and ends with reflection questions. Learning objectives are helpful to readers particularly if they choose

[1] A companion booklet to accompany this textbook is posted on the Resources tab for the book on **collegepublishing.sagepub.com**. It is designed for research teams to use collaboratively to build capacity in carrying out their research within communities.

to read chapters selectively, rather than from front cover to back. However, we highly recommend reading the book from the first to the last chapter at least once to gain understanding of the fluidity of this research approach. The reflection questions are intended to help instructors and can be used on discussion boards for online courses or as platforms for in-person discussions. Community research partners also provide lessons learned and tips that are integrated throughout the book, and each chapter has an associated "key terms" library for quick reference.

AUDIENCE

This text is geared toward people who want to know how to carry out community-engaged research. People using this book will benefit from having some foundational knowledge of research, but a professional background in conducting research is not necessary in order to engage with this book. Examples used throughout the book are drawn from multiple disciplines; as such, strategies noted throughout the text are not discipline specific. Participatory research courses are commonly offered through criminology, sociology, health professions, social work, public health, nursing, community medicine, and anthropology, but the text is not limited to these disciplines or to designated courses on participatory research. The text could be used in an undergraduate research course as an introduction to community-engaged research or adopted for advanced research courses for graduate students in classes like participatory research courses, community-based participatory research courses, and fundamental research courses.

This text is ideal for instructors searching for a textbook with details on how to carry out community-engaged research. Many existing texts focus on one kind of approach (e.g., community-based participatory research, participatory action research) rather than the continuum of approaches as done in this text. This text is also ideal for instructors who want to teach students how to engage in research with marginalized or vulnerable populations. Working with marginalized populations requires specific trust building and engagement strategies not typically detailed in general research texts.

Because this text is written as a how-to guide, it may also be appealing to established researchers who are interested in learning an innovative approach. Even the chapters on research methods are helpful to established researchers as the text details the specific considerations for using traditional research approaches in the context of community engaged research. Finally, established community-engaged researchers could also use this text with their community research partners. The companion materials were designed for community engaged research teams to use collaboratively to build capacity in carrying out their research.

1 HISTORY OF RESEARCH WITH MARGINALIZED AND OPPRESSED COMMUNITIES

This chapter offers a historical overview of the misuse and abuse of research and the subsequent deterioration of trust in research in some communities; the chapter also explores present day research neglect resulting from research that does little to address the needs of the communities being researched and the barriers in place that can prohibit the research findings getting back to communities. We also establish the definition of "marginalized populations" used throughout the text and address how forms of marginalization vary over time and across contexts.

LEARNING OBJECTIVES

- **1.1** Explain the social and structural circumstances of marginalized populations.
- **1.2** Describe historical trauma and harm to marginalized communities caused by research.
- **1.3** Identify how distrust in research differs from mistrust in research.
- **1.4** Summarize how distrust and mistrust in research contribute to reluctance and resistance to research participation.
- **1.5** Interpret how research can neglect protecting community interests and addressing community needs.

History shapes the present day and future in remarkable ways. Historical events have cascading impacts that are felt, in some cases, centuries after the event that continue to impact livelihood, perceptions, intentions, and behaviors. History cannot be changed, but it needs to be understood, acknowledged, and incorporated into present and future planning, approaches, policies, and programs. This book begins with a chapter that highlights the history of research with marginalized communities. Understanding this history is critically important to recognizing and acknowledging the harms that research has caused individuals and communities while

also increasing knowledge and awareness of the historical missteps to avoid in order to create a strengths-based, healthy, and engaging approach to collaborative and inclusive research practices. This chapter begins by framing and contextualizing marginalization and why focusing on marginalized populations is important in community-engaged research.

MARGINALIZED POPULATIONS

Marginalized populations experience restricted access, exclusion, or rejection from necessities and opportunities, exposing them to social-structural disadvantages associated with sex, gender identity, socioeconomic class status, race, ethnicity, religion, geography, and physical and cognitive ability, among other factors. Marginalized populations can be disproportionately harmed by negative implicit biases of their personal characteristics that are corroborated to justify marginalization. Likewise, marginalized populations are often susceptible to discriminatory *isms* like racism, sexism, heterosexism, classism, ableism, and ageism—to name a few. Such discriminatory treatment can surface within interpersonal interactions but discrimination is also embedded within systemic oppression (Feagin, 2013; Liedauer, 2021). The impact of social and systematic marginalization is harmful in that it disempowers these groups compared to more privileged groups who do not encounter the same barriers. In understanding the lived experiences of marginalized populations, the concept of intersectionality cannot be ignored.

Intersectionality considers the role of interlocking or overlapping marginalization in individuals' experiences, treatment, and outcomes (Crenshaw, 1989). Kimberlé Crenshaw introduced the term *intersectionality* to highlight the multidimensionality of Black women's experiences, along the intersection of gender and race, that is often unnoticed or ignored within a "single-axis analysis." She critiques the erasure of multiburdened voices in theorization and antidiscrimination doctrines, arguing for adequate consideration of overlapping forms of marginalization (Crenshaw, 1989). The gender disparities of outnumbered women working in science, technology, engineering, and mathematics (STEM), for example, is compounded by the racial and ethnic disparities for Black, Indigenous, and Women of Color (BIWOC) in these fields (Anderson et al., 2021; Carlone & Johnson, 2007; Charleston et al., 2014). Likewise, shared experiences among women can differ at the intersection of race and class, as demonstrated within maternal health and the high maternal mortality rate for marginalized Black women compared to their white counterparts (Patterson et al., 2022). For marginalized populations, the intersectionality of multiple marginalized characteristics should be of consideration in theory, politics, and social practices.

Of note, the forms and extent of marginalization vary over time and across contexts. For instance, bureaucratic responses to public health matters can vary by geographical location, as seen with legal restrictions and criminalization of pregnant people seeking abortions in the United States (Basmajian, 2024; McFarlane & Hansen, 2024). Changing political climates, social norms, and institutional cultures can alter treatment toward marginalized groups over time, for better or worse. International events can lead to public outrage as well as new or revamped immigration policies, which can marginalize certain immigrant groups—as demonstrated by the United States' communal and political disdain toward undocumented

immigrants from the Northern Triangle countries of Central America (Honduras, Guatemala, and El Salvador) during the Trump administrations. On the contrary, global events also lead to political decisions and public support to aid marginalized populations, which is evident with sheltering and supporting asylum seekers who have fled from persecution in their countries of origin. Much like fluctuating political climates, fluctuating public health concerns can also elicit social-structural burdens and affect the degree of marginalization directed toward certain groups over time. For instance, widespread misinformation and public fear of HIV/AIDS in the 1980s was coupled with assumption, stigmatization, and isolation of the LGBTQIA+ community and violence toward anyone perceived to be within this group (Boudreau et al., 2022; Bratina et al., 2020). With time, informed awareness, and some medical advancements, the misguided anger subsided as public misinformation dwindled. Similar fear and ignorance about public health concerns shaped the social isolation of Asian Americans at the height of the COVID-19 pandemic in 2020 (Lee & Waters, 2021; Wang et al., 2020).

Historical injustices and social-structural disadvantages follow marginalized populations through generations, shaping intergenerational trauma. A prime example of intergenerational trauma experienced by a marginalized population has resulted from the United States War on Drugs in which punitive drug policies during the 1980s and 1990s exposed Black communities to hypersurveillance, criminalization, and excessive prison sentencing guidelines (Bush-Baskette, 2010). The intergenerational impact of the War on Drugs has perforated Black communities through lingering social harms from incarcerated family members with lengthy prison sentences, psychosocial changes that impact familial relationships, and the long-lasting restrictions to personal growth due to continuous carceral oversight (Bush-Baskette, 2010). With the turn of the 21st century, there have been substantial policy changes at the federal and state level that have introduced more community-based alternatives to incarceration and made progress in decriminalizing cannabis. As a result of these changes, some argue that the punitive policies and marginalization from the War on Drugs are limited to the past; however, this negates the reality that consequential marginalization, human suffering, and social harms can remain prevalent over time despite systemic efforts for rectification.

There are professional and social responsibilities to acknowledge and uphold when working with marginalized populations. For instance, it is important for educators to consider educational disadvantages and intergenerational trauma in their efforts to adequately meet students where they are in their education journey and to bridge gaps in educational attainment. Social and psychological practitioners should be mindful of social disadvantages and systemic barriers when working with marginalized populations to ensure they are adequately and appropriately providing services, particularly when these services have been disproportionately limited or withheld from marginalized groups. Likewise, researchers have a responsibility to recognize and protect marginalized populations that are associated with their research studies. By focusing on the concept of *marginalization*, this book takes a more inclusive approach to research protections than what is currently considered in federal guidelines that focus on *vulnerability,* as stated by the U.S. Office for Human Research Protections (OHRP). The Code of Federal Regulations (Title 45, Code 46) highlights the need for additional protections for groups deemed as "vulnerable populations": prisoners, children, and pregnant women, human

fetuses, and neonates. This list of "vulnerable populations" defined by the OHRP is limited in scope, however, given that it excludes marginalized groups who are isolated from necessities and opportunities and overburdened with social-structural disadvantages. Marginalized populations deserve research protections to compensate for their social positionality, and researchers have a professional responsibility to avoid research protocols that reinforce further oppression.

> "[I]nformants or political activists living under authoritarian regimes [. . .] could face significant danger if any compromising information about their identities were published. Even in liberal democracies, political activists who challenge authorities or break the law as part of their practice may also face legal and other dangers. Moreover, subjects may also be vulnerable and marginalized because of their position in the social and political hierarchy, and may face a range of possible reprisals even for perfectly legal actions. Being attentive to the ways in which vulnerability and marginalization are constituted vis-a-vis specific research questions is crucial in order to mitigate risk." (Lake et al., 2019, p. 1)

We argue that in planning and executing research studies, researchers must consider and account for existing marginalization to avoid imposing further trauma or exploitation of marginalized populations. Without adequate protections of marginalized and oppressed communities, researchers run the risk of research misuse and abuse that unfortunately has found its way into some research. Importantly, there is not a one-size-fits-all approach to research involving marginalized communities. Throughout this book, however, we offer strategies to build connections between academic researchers and community partners that help support inclusive research practices, minimize harm caused by researchers, and increase the impact of research within marginalized communities. Finding the right research approach should be developed to "fit" specific communities. Understanding historical trauma and harm caused by research on marginalized communities is a critical first step in community-engaged research.

HISTORICAL OVERVIEW OF RESEARCH MISUSE AND ABUSE

Traditional research in the social sciences focuses on knowledge production as the goal. As a result, marginalized populations are often exposed to research that aims to uncover nuances in various subject matters, to share personal insights about their unique circumstances or experiences, and to reveal answers to disputed questions or share potential solutions to unresolved issues. Notwithstanding the benefits of gaining valuable knowledge from research endeavors, traditional research is immersed in a power imbalance between the researchers and "the researched," conjoined with research ideologies and methodologies that reproduce this differential power dynamic. As such, marginalized populations have historically been targets of research abuse and susceptible to the misuse of research as a method to advance knowledge. By way of example, we discuss several research projects that exhibit the generational harm and trauma that has historically occurred throughout the world at the hands of researchers.

Syphilis Study at Tuskegee

The **Syphilis Study at Tuskegee** (1932–1972) was conducted by the U.S. Public Health Service (USPHS) to better understand the syphilis disease and its long-term effects until death. This Tuskegee Syphilis Study included 600 Black men in Macon County, Alabama of which 201 tested negative for syphilis and 399 tested positive for syphilis but were not informed of their syphilis status. The Black men were told that they would be treated for "bad blood" (i.e., a colloquialism for general ailments) in exchange for free medical care, food, and insurance coverage for burial. This government-funded medical research experiment did not receive the full informed consent of the men to participate; in fact, they were betrayed to believe that they were getting free medical care that was not contingent upon their experimentation. The study was also racialized and classist in that it recruited from Macon County, Alabama (a primarily Black and poor area), to specifically target Black men and subject them to misleading information; then, it coerced impoverished Black men to participate in the study for access to several free resources, which posed an undue influence on this marginalized population given their socioeconomic status. Furthermore, when penicillin became available as a widely used treatment for syphilis, the USPHS had the ability and power to provide the participants with penicillin. Instead, the medical researchers abused their power and denied participants their right to medical treatment in order to continue studying untreated syphilis. In the absence of needed medical treatment, the untreated syphilis spread to the men's partners, harming their families and communities, and leading to the early death of these participants. In 1997, U.S. president Bill Clinton issued a formal presidential apology for the unethical research and harmful outcomes at the hands of the USPHS Syphilis Study at Tuskegee, that lasted 40 years.

Nazi Euthanasia Program

Under the premise of German National Socialism preceding and during World War II, Nazi doctors were tasked with rebuilding the population by improving the "racial health" and "racial purity" of its populace. During the 1930s, doctors identified individuals who were suspected of having genetic diseases that were threats to "hereditary public health" (like schizophrenia, epilepsy, blindness, and deafness, to name a few). The government required these individuals to undergo sterilization to prevent them from procreating another generation with illnesses that were deemed to be problematic for the overall mental and physical health of Germany's population. However, this forced sterilization was part of a racial hygiene program that turned into the widespread murders of people deemed "not worthy of life" according to a eugenics-focused selection process by Nazi doctors. During World War II, Nazi doctors conducted a series of experiments on marginalized populations confined in Auschwitz concentration camps, killing them for research purposes under the guise of "euthanasia" since they were believed to be already destined for death. The perceived causation between eugenics and poor medical health welcomed the objectification of human beings that condoned the **Nazi Euthanasia Program** and the Holocaust's medically sanctioned genocide (1930s–1940s). The doctors involved were charged with war crimes and crimes against humanity in the Nuremberg Medical Trials (1946–1947), which established participant rights and developed research principles known as the Nuremberg Code.

Milgram Obedience Studies

Given the concern about doctors' role within the Nazi Euthanasia Program as it concerned their obedience to authority compared to their individual empowerment, Dr. Stanley Milgram was motivated to conduct the **Milgram Obedience Studies** (1960s). He examined the extent that people would obey authority figures if this obedience entailed harming others. The research participants were given the role as "Teachers" and were led to believe that there was a person in an adjacent room who was the "Learner" undergoing a word-pair test. The research participants were instructed to administer a punishment–in the form of an electric shock–for any wrong answers from the "Learner," although there was no real person in the adjacent room. The study revealed how far people were willing to go to continuously shock a stranger in punishment, despite verbal pleads to stop and at an increasingly higher voltage. About 65% of the participants administered shocks at the highest voltage of the perceived shock board, suggesting that people are highly obedient to authority figures despite causing pain to another individual in the process. Yet, the Milgram Obedience Studies raised serious concerns about potential coercion from those with relative power, in which study participants feel pressured to engage in research activities due to the perceived power of researchers. Additionally, the Milgram Obedience Studies imposed excessive emotional harm and anxiety on the research participants from the study's deception, coupled with the lack of a debrief or insufficient debriefing after the study. A notable contribution to obedience literature within social psychology, the Milgram Obedience Studies remain infamous as a cautionary example of deceptive harms and debriefing failures.

Tearoom Trade Study

Dr. Laud Humphrey's **Tearoom Trade Study** (1966–1968) explored impersonal sex as a form of human interaction, with a focus on homosexual acts committed in public places known as "tearooms." As part of this dissertation research, Humphreys observed gay men and their sexual activity within public park restrooms. He integrated himself into the study by hiding his identity and role as a researcher and, instead, posing as a lookout (known as the "Watch Queen") to notify the men of a potential intrusion. After posing as a "Watch Queen," Humphrey proceeded to collect identifying information about the men by writing down their license plate numbers, which were used to collect names and addresses using a license registry. He subsequently visited the men in their homes pretending to be a part of a social health study and, under false pretenses, took advantage of this opportunity to collect survey data from them. The Tearoom Trade Study raised ethical concerns about consent and deception, particularly with a marginalized population during a time period that was filled with homophobic propaganda.

Stanford Prison Experiment

The **Stanford Prison Experiment** (1971) was conducted by Dr. Philip G. Zimbardo at Stanford University to examine the psychology of prison life by creating a mock prison environment with college students. Zimbardo used the basement of the Stanford University Psychology Department to simulate a prison environment in which 24 male college students were assigned roles as prison guards or incarcerated persons. The Stanford Prison Experiment was originally

intended to be a 2-week psychology experiment on the psychology of mock prison life but was stopped after 6 days due to cruelty that surfaced and the harm caused to the research participants. A third of the participants acting as prison guards quickly started to behave sadistically, getting pleasure in harming and humiliating the participants who were posing as incarcerated persons. It became evident that the experiment was causing harm to the mental and emotional well-being of the assigned "prisoners" who were fatigued, distraught, disoriented, enraged, and exhibited uncontrollable crying. Although Zimbardo maintained that the Stanford Prison Experiment provides insight into how one's social environment and having (or lacking) power shapes human behavior, this conclusion was formulated as a byproduct of several ethical issues in his research. For instance, the study's introductory orientation for the assigned "prison guards" encouraged cruel behavior since the participants likely acted in the way that was expected of them from an authority figure, affecting the study outcomes. Relatedly, the students assigned to be "prisoners" were deceived about the treatment to expect as part of the experiment, notably the overall degradation and inhumanity. Their requests to leave the mock prison environment were reciprocated with commentary about the environment and their assigned role under confinement that essentially denied requests to withdraw from the experiment—another notable ethical issue of the Stanford Prison Experiment.

Havasupai Tribe vs. Arizona State University

Tribal land is particularly important for indigenous communities as tribal land has cultural, spiritual, generational, and quality-of-life meanings and values that require protection, especially from the long history of governmental confiscation of tribal land. As explained by Orr et al. (2021, p. 66), "This stewardship comes from a spiritual obligation to protect the land and to exercise that authority, and in addition, likely a sense that tribal land had been violated and appropriated in the past and the importance of preventing that from happening again." Still, during the 1990s, hundreds of tribal members of the Havasupai Indian tribe gave their consent to Arizona State University to extract samples of genetic material for a diabetes study. In 2003, the Havasupai tribe learned that their DNA samples had been stored and later used to study other topics including, but limited to, schizophrenia and inbreeding. The ***Havasupai Tribe vs. Arizona State University Board of Regents*** lawsuit was settled in 2010, under the premises that there was a lack of full informed consent and there was more than minimal risk to the Havasupai tribe. More specifically, the researchers did not receive the tribe's full informed consent to use their DNA blood samples for research other than diabetes research (Drabiak-Syed, 2010; Orr et al., 2021). The use of their blood samples for subsequent, unrelated studies was a violation of the tribe's trust and their consent to the diabetes research. The tribe argued that subsequent studies were misuses of their blood samples since the tribe would not have consented to this research due to cultural and spiritual meanings of blood (Drabiak-Syed, 2010; Orr et al., 2021). Thus, the subsequent studies were attempts to produce knowledge about the tribe, but the research posed substantial risk and harm to the Havasupai tribe and their cultural and spiritual beliefs. Within the larger sociopolitical context of colonization, the *Havasupai Tribe vs. Arizona State University Board of Regents* lawsuit is only one of many examples exploiting Indigenous groups for knowledge production, furthering their marginalization when

researchers lack cultural integrity and studies reinforce the erasure and erosion of tribal heritage (Battiste, 2016).

These infamous studies are a select few of the many abuses of power embedded within past research that have misled, coerced, objectified, and experimented on human beings in the name of science. Restricted, excluded, and rejected from access to necessities and opportunities, marginalized populations are susceptible to being researched as figurative objects to benefit knowledge production, but they often do not receive reciprocal tangible benefits from this research. This one-sided exchange is evident in the above examples—to name a few—of the Black men in the Tuskegee Syphilis Study, for the gay men in the Tearoom Trade Study, and for Indigenous peoples pricked and prodded by academic and medical institutions. Individuals in these studies have been subjected to exploitation for research purposes, showing that knowledge production has been prioritized at the expense of imposing harm on those involved. There was an outright understanding that some harm was expected and permissible if it was for the greater good of society, yet under this premise, researchers knowingly caused harm under the guise of what is *reasonable* compared to individual and societal benefits. Furthermore, this notion of reasonableness is subjective, depending on the target group for research. In fact, history demonstrates that even well-intended research studies are not exempt from causing harm—particularly to those in marginalized and oppressed communities. Although physical harm is arguably the most visible to the naked eye, harm resulting from research participation can be psychological, social, communal, and multigenerational. As such, research practices that were once widely accepted and even government or medically sanctioned for knowledge production, are now recognized as being problematic and unethical.

DISTRUST AND MISTRUST IN RESEARCH

Harmful research is not only a violation of trust, but harmful research also contributes to apprehension toward research and a deterioration of trust in research moving forward. Having trust in research generates some confidence in the methods and the researchers involved, shaping a willingness to participate in the research; however, distrust and mistrust in research brings about a reluctance or outright rejection and resistance to research participation. The concept of **distrust** is the firm belief that an entity is untrustworthy; in other words, distrust is an established lack of trust or confidence in someone or something. **Mistrust** is its own unique concept, different yet related to the concept of distrust. Mistrust is less about a binary determination of whether there is trust, but rather entails an assessment process of evaluating for trustworthiness that evokes thoughts and feelings of doubt and skepticism (Citrin & Stoker, 2018).

Mistrust in research can show up as a skepticism that researchers conduct research for their own personal gain and career trajectory. This presumption is further compounded when participants are harmed in some capacity and yet the study generates professional advances for the individual investigators who conducted the study. Still, mistrust is not restricted to interpersonal relationships with researchers, but there is also system-level mistrust in the government at large and in medical institutions that have allowed research exploitation and did not protect groups from harm. Jaiswal and Halkitis (2019, p. 80) argue that we should "locate mistrust

as a phenomenon created by and existing within a system that creates, sustains and reinforces racism, classism, homophobia and transphobia, and stigma." Mistrust is typically not a result of isolated or individual incidents but systemic, multiplicative, and continuous harms and the impact of socio-structural injustices on people's lived experiences.

In the historical context of research that has exploited marginalized populations, there is a distrust and mistrust of research in some communities more than others, namely the most marginalized communities. Without trust and with concerns about research motivations, marginalized populations are reluctant to participate in research. In the United States, there is currently an underrepresentation of Black participants and members of the LGBTQIA+ community in medical studies—an underrepresentation that is largely attributed to medical mistrust (Jaiswal & Halkitis, 2019; Sharma & Palaniappan, 2021). Widespread mistrust in research is also evident within Indigenous communities in the United States and Australia, which is attributed in part to historical politicized events like broken treaties as well as forced removals and relocation (Burnette et al., 2011; Orr et al., 2021). Such historical events and traumatic experiences that harm marginalized communities impact their beliefs of trustworthiness, fueling mistrust in these larger systems and creating a resistance or rejection of research participation that could potentially cause more harm.

The skepticism among marginalized populations about research participation is grounded in the belief that the research, researchers, and research institutions—as a collective entity—are not acting in the community's best interests (Jaiswal & Halkitis, 2019). To help protect research participants, it has become commonplace to have research review boards like the **institutional review board (IRB)** in the United States, also known as the **research ethics board (REB)** in other countries like Canada. Research review boards evaluate proposed research methods to make sure they are in accordance with research regulations to protect the participants and ensure ethical standards are met. However, despite modern-day research protections through institutional review boards (IRB), the guidelines used to evaluate the ethical standing of research studies are individualized in focus. More specifically, research review boards "are primarily focused on the principle of assessing risk to individuals and not to communities and continue to perpetuate the notion that the domain of 'knowledge production' is the sole right of academic researchers" (Flicker et al., 2007, p. 478). There continues to be a differential power imbalance between researchers and the "researched" that reinforces a research focus and objective of knowledge production, alone, without consideration of communal risks.

In response to community distrust and mistrust in research coupled with the weak IRB consideration of communal risks, some Indigenous tribes have developed their own community review process, with a designated review board tasked with establishing and communicating research guidelines that align with tribal values. As written by Kuhn et al. (2020, p. 279), "These entities play critical roles in ensuring that studies based within tribal settings maximize the benefits and minimize the risks of research to tribal communities by protecting tribal knowledge systems from cultural appropriation, exploitation, and misuse." In their content analysis of six tribal institutional review board application processes, Nicole S. Kuhn and her colleagues (2020) found some application elements that were more prominent compared to those typically found within traditional IRB applications. This includes, but is not limited to,

GUIDING PRINCIPLES OF TRIBAL INSTITUTIONAL REVIEW BOARDS

"A fundamental principle that emerged from this work was honoring tribal sovereignty. This is an important point because, in some cases, these boards are granted governing authority to act on behalf of the tribal nation's interest. In addition, researchers should note that when they are obtaining approval from the tribal governing bodies, they are in essence gaining the consent of these tribal nations at a government level, and then they must also navigate toward gaining consent from other segments of the community and individuals. A second overarching principle of consequence was the advancement of Indigenous research ethics. In particular, all boards were tasked to ensure that the risks are minimized, and benefits maximized. For most tribes, risks must be considered for their community, individuals, as well as greater risks that might jeopardize their treaty rights or exploit traditional knowledge systems. Furthermore, tribes also want to see benefits at all levels within their social structures. Some benefits are the strengthening of research capacity building, useful study results, achieving community level goals, and meaningful and respectful expressions of internal tribal values and culture. Finally, a less common principle, but one that affirms tribal values, is to protect natural resources for both present and future generations." (Kuhn et al., 2020, p. 286)

an agreement that the research data is owned by the tribal nation and should be returned to the tribal government once the study is complete, as well as the board's approval before publishing results or disseminating data outside of the tribe. Given the long-term history of research exploitation of Indigenous groups and the misuse of data collected from them (Drabiak-Syed, 2010; Orr et al., 2021), it is no surprise that the tribal review boards place great emphasis in protecting tribal priorities in data ownership, data management plans, and approving any proposed publications or data dissemination efforts. Without sufficient community input of fundamental guiding principles or community engagement in the development or review of research proposals, research runs the risk of misuse and abuse that exacerbates mistrust in research and increases the risk of neglecting community needs.

PRESENT-DAY RESEARCH NEGLECT IN ADDRESSING COMMUNITY NEEDS

One way for researchers to combat community mistrust in research is to recognize community interests within research efforts and to address community needs. Often, traditional approaches to research—in theory and practice—do little to address the identified needs of the communities being researched and often do not funnel research results back to communities. Given that marginalized populations experience social-structural disadvantages associated with gender identity, class status, race, ethnicity, religion, geography, and physical and cognitive ability, the existing disparities for marginalized populations should be studied and understood within the context of macro-level, systemic oppression. For instance, institutional racism contributes to the racial inequities we see across various fields like health care, the criminal legal system, and

academia (Bonilla-Silva, 2021; Elias & Paradies, 2021; Lee, 2024), but neglecting to contextualize individual experiences within racialized systems does not account for institutional racism and restricts transformative change for minoritized groups.

Forms of knowledge production that neglect the community can also manifest as "helicopter research" (or similarly called "hit-and-run" and "drive-by" research). The premise of **helicopter research** is that researchers enter communities as outsiders, collect data from the community experts, and then leave the community with data but without reciprocating the gained knowledge for any tangible action. Helicopter research does not fully consider or adequately implement reciprocal benefits for the community, neglecting community needs and fueling mistrust in the research process. Such exploitative research further reduces any power that marginalized populations may have in society, reinforces social-structural problems (since they are not addressed), and then contributes to the power imbalance experienced by marginalized populations compared to other more privileged groups. This poses a cyclical effect in which the information gained from marginalized populations is not used to promote change, and thus the "researched" continues to be studied to pique the interests of other researchers without meeting the needs of the community.

As much as researchers value understanding community problems, they must also strive to protect community interests and address community needs to avoid the misuse of research and abuse of research participants. Research that is not safely disseminated or accessible to the community or that is full of academic jargon and unclear to the community is precariously neglectful and poses barriers that interfere with the research findings getting back to communities and providing benefits to them. Furthermore, research that uses data from communities to better understand a phenomenon or to test interventions that does little to address the needs of the researched community is intentionally neglectful. There are countless examples of historical and present-day medical research, for example, that developed cutting edge medical procedures or tested medications to address chronic health conditions that, when approved for use in practice, were not accessible to even the research participants, let alone the communities they lived within (Moore, 2022).

Some researchers falsely claim they "give voice" to marginalized populations through the dissemination of their research. This rhetoric of "giving voice" to the "voiceless" is embedded in a hierarchical power dynamic that places power in the hands of the researchers to "give them voice." It is patronizing to use language of "giving" voice to people when they already have a voice—albeit one that remains ignored, belittled, and undermined. This rhetoric also centers this supposed "giving voice" as a goal of research *on* marginalized populations in lieu of actionable change *with and for* marginalized populations.

CONCLUSION

Notwithstanding legitimate concerns about research and existing reservations to participate in research, it is crucial and valuable to include marginalized populations as meaningful partners in research to improve the overall well-being of marginalized groups and to address community needs. A community-engaged research paradigm recognizes the community as community

experts, develops and promotes an equitable partnership with the community, and creates an avenue to build mutual trust as all parties work collaboratively on shared priorities. This book is intended to provide readers with the knowledge, skills, and strategies needed to carry out community-engaged research with marginalized populations.

REFLECTION QUESTIONS

1. Reflecting on the concept of intersectionality, what are the potential risks of conducting research with communities that have experienced historical trauma or marginalization?
2. What are some examples of research misuse and abuse? What could have been done differently during these research studies to be more ethically and morally responsible?
3. In what ways can your research practices be shaped by an awareness of historical harm or past research exploitation of marginalized populations?
4. How can you identify potential power imbalances that might emerge in your community-engaged research project?
5. How does community-engaged research work to combat community mistrust or distrust in research broadly speaking?
6. Reflect on what steps you can take to ensure that your community-engaged research project does not equate to helicopter research. In other words, what strategies can you use in the development of a community-engaged research project to ensure that the community needs are addressed in some capacity?

KEY TERMS

distrust
Havasupai Tribe vs. Arizona State University Board of Regents (2010)
helicopter research (similarly called "hit-and-run" and "drive-by" research)
institutional review board (IRB), also known as the research ethics board (REB)
intersectionality
marginalized populations
Milgram Obedience Studies (1960s)
mistrust
Nazi Euthanasia Program (1930s–1940s)
Research ethics board (REB), also known as the institutional review board (IRB)
Stanford Prison Experiment (1971)
Syphilis Study at Tuskegee (1932–1972)
Tearoom Trade Study (1966–1968)

2 PHILOSOPHY AND PRINCIPLES OF COMMUNITY-ENGAGED RESEARCH

This chapter dives into the roots of community-engaged research and its underlying principles including alignment with social justice, health equity, cocreating knowledge, and power sharing. We conceptualize "community" and explore the many ways community is defined. We also describe why the application of community-engaged research is not one-size-fits-all and will differ from one community to another.

LEARNING OBJECTIVES

- **2.1** Define *community-engaged research* and the core principles.
- **2.2** Summarize a brief overview of the history of community-engaged research.
- **2.3** Demonstrate understanding of how community-engaged research can promote social justice and health equity.
- **2.4** Appraise the quality of existing community-engaged research projects.
- **2.5** Identify the many ways *community* is defined.

Inclusive practices and processes in research are critically important to ensuring ethical practice with marginalized and historically oppressed communities. Creating an inclusive research approach reduces the risk of harm from research to communities while recognizing people with lived experience as experts in the solutions needed to create change. Community-engaged research, when done correctly and authentically, can address inequities in the research process, improve community outcomes, and promote sustainable change (Wallerstein et al., 2020). In this chapter, we provide a definition of *community-engaged research* by exploring the history of this research approach and examining its alignment with social justice and health equity. We also provide an overview of the principles that define community-engaged research and underlying epistemology of this approach. This foundational knowledge will help researchers and community members discern high quality community-engaged research projects.

DEFINING *COMMUNITY* AND *ACADEMIC*

Within the context of community-engaged research, how is *community* defined? Who are "academic" partners? On the surface, these questions may seem obvious yet in practice they require deep thought and attention. There is not a simple answer for how community is defined, although there is clear agreement in the literature that defining *community* is essential (Israel et al., 2008; Haapanen & Christens, 2021). A **community** may consist of a mix of stakeholders or a collective, residents living geographically near one another, constituents, users of services, providers, advocates, people with a shared value or identity, community-based organizations, networks, and community leaders (Israel et al., 2008; Vaughn & Jacquez, 2020). The concept of community is not homogeneous; it can and does mean many different things. Residents, practitioners, leaders, and organizers, however, can all have different experiences, privileges, power, and access. Thus, community-engaged research may include any mix of community members from residents to service providers. Particularly with marginalized communities, caution should be taken as projects are developed to ensure the right mix of people are involved to develop and answer the research questions at hand. For example, some forms of community-engaged research may refer to practitioners as the "community," but service providers may not have a sense of the challenges faced by people who use the services. As such, if a research project is centered on improving mental health care, it is quite possible that practitioners and consumers will have different perspectives and experiences (Haapanen & Christens, 2020). Failure to include people closest to the research problem may result in reinforcing existing inequities or not being fully responsive to the community's needs. At the same time, it is important to remember that people have overlapping identities. They may be a practitioner *AND* a member of the community of focus.

> "While a community group that is controlled by residents will likely reflect that community's own interests, professional practitioners serving that community may have other interests—those of their profession's particular guild, for example—that are not necessarily aligned with residents' priorities. Researchers choosing to work with community partners without awareness of these dynamics may therefore reinforce or even exacerbate existing power disparities." (Haapanen & Christens, 2021, p. 3)

Academic partners are a little more straightforward to define. Partnerships in community-engaged research typically refer to "academic researchers" partnering with some combination of community residents, providers, organizations, government officials, or other stakeholders to carry out research. These partnerships are also referred to as community-academic partnerships. In general, an academic researcher is employed by a university or college to teach in their area of expertise and conduct research and service. Some academic researchers may work at research-intensive universities or independent research centers where more of their time

is devoted to research and knowledge dissemination (e.g., writing about research, presenting research). Just as practitioners can also be members of "the community," so too can academic researchers. Academic researchers may have lived experience with their topic of focus or reside in a community that is involved in research.

WHAT IS COMMUNITY-ENGAGED RESEARCH?

In this text, we utilize a definition of community-engaged research that incorporates the work of scholars over the past several decades. The Centers for Disease Control (CDC; 1997) define community-engaged research as

> . . . the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people . . . . It often involves partnerships and coalitions that help mobilize resources and influence systems, change relationships among partners, and serve as catalysts for changing policies, programs, and practices. (p. 9)

Israel and colleagues (2010) emphasize equity in their definition suggesting community-engaged research is a "partnership approach to research that equitably involves community members, partitioners, and academic researchers in all aspects of the process, enabling all partners to contribute their expertise and share responsibility and ownership," (p. 2094). The definition provided by Israel and colleagues (2010) reflects a specific community-engaged research approach called community-based participatory research (CBPR). However, we argue that authentic and truly *engaged* community-engaged research requires a definition that highlights equity and joint ownership alongside collaboration and partnership noted in the CDC definition. Thus, in this text, our working definition of community-engaged research brings together pieces of the CDC and Israel et al. (2010) definition.

Community-engaged research is an umbrella term that refers to a spectrum of research approaches that focus on meaningful community and academic collaboration and partnership that include building trust, promoting equity, and sharing power throughout the research process. Community-engaged research is not a specific methodology but rather a mission-driven approach that can use a variety of research designs (e.g., survey, randomized control trials, mixed methods, quasi-experimental designs, grounded theory), data sources (e.g., administrative data, self-report, interviews), and analytic approaches (e.g., quantitative, qualitative). Many more specific approaches fall under the community-engaged research umbrella including CBPR, which is most noted in literature (Haapanen & Christens, 2021). Other approaches include participatory action research (PAR), citizen-led, street PAR, community driven or led research, and patient-centered outcomes research, to name a few. In Chapter 3, we define the myriad approaches in the community-engaged research spectrum.

HISTORY AND EVOLUTION OF COMMUNITY-ENGAGED RESEARCH

The use of community-engaged research approaches has proliferated in the past two decades, yet these approaches have deep, historical roots documented in the social sciences, psychology, public health, social work, and geography. Action research, in particular, dates to the 1940s with social psychologist Kurt Lewin's work that challenged positivist epistemology by creating a cyclical model of research that involved planning with study participants and students, action, and examining the impact of the action (Duke, 2020; Duran & Wallerstein, 2003). "Action anthropology" was later noted in Sol Tax's work with Indigenous populations in the rural Midwest (Duke, 2020).

By the 1970s, participatory action research emerged via anti-colonial movements that challenged the ways knowledge was developed and decided upon, particularly knowledge about marginalized communities (Cornish et al., 2023). Paulo Freire's emancipatory research played a critical role in shaping the epistemology and mission of participatory action research (Duke, 2020). At the same time, Colombian sociologist, Orlando Fals Borda, developed his own version of participatory action research that he utilized to initiate change during social movements in South America. Through this work, he established the La Rosca de Investigación y Acción Social, which translates to the "Circle of Research and Social Action" (Pereira & Rappaport, 2021). During this period, scholars pushed to transform the research paradigm: "Rather than viewing research as neutral, participatory research intellectuals adopted the goals and commitment to critical consciousness, emancipation, and social justice as they challenged their own roles in communities," (Wallenstein & Duran, 2003, p. 30).

In the 1990s, terms like CBPR and participatory research were more prominent in contemporary literature. Loretta Jones and Keith Norris coined the term *community partnered participatory research* (CPPR) through their collaborative work and several Centers for Disease Control and Prevention funded research projects in 1992 (Jones, 2018). In the late 1990s, W. K. Kellogg developed one of the first funded CBPR training programs called the Community Health Scholars Program (1998–2007). The program provided post-docs the training to engage in CBPR to eliminate health disparities. For purposes of the training program, CBPR was defined as "a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities" (Griffith et al., 2009, p. 338).

Contemporary approaches that fall under the umbrella of community-engaged research are extensive in literature, funding mechanisms, and research training programs. Although *action research* remains a common term, CBPR is the most widely noted and utilized approach (Haapanen & Christens, 2021). Systematic reviews find community-engaged research approaches noted in research on health promotion (McMullen et al., 2020), public health (Israel et al., 2013), randomized control trials on new interventions (Solomon et al., 2009), criminal-legal systems (Payne et al., 2017), addressing health disparities (Williamson et al., 2021), as well as many more areas. The Robert Wood Johnson Foundation funds several leadership programs

to train academic and community scholars to conduct community-engaged research. Federal funders, like the National Institutes of Health (NIH), expect some level of community engagement in proposed research while the Institute of Medicine recognizes the need for community engagement through all phases of clinical trials (Balls-Berry & Perez, 2017). In fact, in 2023, the NIH launched a funding mechanism for community driven research to enable communities to examine the structural drivers of health and health promotion.

Much of the noted history informs the evolution of action research. However, in disciplines like community psychology, social work, and applied social sciences, community engagement throughout the research process is in the fabric of the discipline. Engagement between academic researchers and community members is one important component of community-engaged research; however, there are other principles and philosophies discussed below that guide this approach to research. Looking back on history and how action research has evolved, the approaches used by Kurt Lewin involved engagement and participation with his university students and the community of study participants. Although action to create change was part of his method, action to create structural change and to disrupt existing systems within the emancipatory research approach was not the primary driver of Lewin's work; rather, Lewin's work primarily focused on collaborative research for creating and testing solutions to problems. The degree of community partnership and collaboration as well as the underlying mission of the work creates a spectrum of community-engaged research approaches. What unites community-engaged research approaches, however, is the set of core principles that guide this work.

PHILOSOPHICAL UNDERPINNINGS AND CORE PRINCIPLES OF COMMUNITY-ENGAGED RESEARCH

The spectrum of community-engaged research entails approaches that are united through the underlying philosophy (or mission) and core principles. We argue that research identified as *community-engaged* requires meaningful and authentic engagement that promotes both equity and social justice throughout the partnership process. In this section, we first define and describe equity and social justice as it relates to the research and partnership process. Next, we describe core principles of community-engaged research and how these principles facilitate the underlying missions of equity and social justice. When preparing for research, it is crucial for the community and academic partners to understand the following philosophical underpinnings and ensure that these core principles remain grounded in any attempts to carry out a community-engaged research approach. Research endeavors lacking these foundational principles do not equate to community-engaged research, as conceptualized.

Equity and Social Justice

Although some may mistakenly use *equality* and *equity* interchangeably, these concepts are not one in the same, and they each have their own unique meaning. On the one hand, **equality** entails the same treatment for all parties involved, regardless of disparate starting points or disproportionate circumstances among and between them. While equality may appear to be

beneficial in some situations, equal treatment across groups is not sufficient to counterbalance social and structural disparities. In other words, equal treatment does not create equitable circumstances and can be more harmful for marginalized populations that battle with several, overlapping disadvantages. On the other hand, **equity** entails meeting groups where they are, to meet specific needs and address specific demands based on their social position. Working toward equity implies working to outweigh social and structural disparities, allowing for fairness and inclusivity across social groups.

It is well established that **social inequalities** have a direct impact on the health and well-being of individuals, families, and communities (Arcaya et al., 2015). This impact creates disparities in mental health, physical health, and quality of life and are prominent across marginalized groups. Marginalized communities, in particular, battle with a wide variety of social inequities revolving around gender identity, class status, race, ethnicity, religion, and physical and cognitive ability, among others. Braveman and colleagues (2011) define these health disparities as *injustice*:

> Health disparities are systematic, plausibly avoidable health differences according to race/ethnicity, skin color, religion, or nationality; socioeconomic resources or position (reflected by, e.g., income, wealth, education, or occupation); gender, sexual orientation, gender identity; age, geography, disability, illness, political or other affiliation; or other characteristics associated with discrimination or marginalization. These categories reflect social advantage or disadvantage when they determine an individual's or group's position in a social hierarchy. Health disparities do not refer generically to all health differences, or even to all health differences warranting focused attention. They are a specific subset of health differences of particular relevance to social justice because they may arise from intentional or unintentional discrimination or marginalization and, in any case, are likely to reinforce social disadvantage and vulnerability. Disparities in health and its determinants are the metric for assessing health equity, the principle underlying a commitment to reducing disparities in health and its determinants; health equity is social justice in health. (p. S150)

Thus, striving to reduce or eradicate social inequities to allow for more equitable circumstances are efforts that help promote a more just society is **social justice**. Providing marginalized groups with the same resources that are given to more privileged communities entails equal treatment that does not address disparate circumstances or promote social justice. Instead, this uniformity maintains a social imbalance and contributes to social harms to marginalized communities. Where there is a greater need, there should be sufficient resources to meet those needs for more equitable circumstances. When there are numerous disadvantages, there is a considerable demand for opportunities and support for more equity. This reality is integral to the planning and partnership process in community-engaged research. In working toward equity and social justice as the underlying mission of community-engaged research, it is critical that academic partners who plan to engage in community-engaged research first educate themselves about the history of oppression and harms to communities they plan to work with.

THE EQUITY MANIFESTO

It begins by joining together, believing in the potency of inclusion, and building from a common bond.

It embraces complexity as cause for collaboration, accepting that our fates are inextricable.

It recognizes local leaders as national leaders, nurturing the wisdom and creativity within every community as essential to solving the nation's problems.

It demands honesty and forthrightness, calling out racism and oppression, both overt and systemic.

It strives for the power to realize our goals while summoning the grace to sustain them.

It requires that we understand the past, without being trapped in it; embrace the present, without being constrained by it; and look to the future, guided by the hopes and courage of those who have fought before and beside us.

This is equity: just and fair inclusion into a society in which all can participate, prosper, and reach their full potential. Unlocking the promise of the nation by unleashing the promise in us all. (PolicyLink, Lifting Up What Works, 2018)

If you imagine community-engaged research as a painting, then equity and social justice would be the canvas. Paintbrushes are used to put color across the canvas but without the canvas, there is no painting. In the realm of research, this means thoughtful planning is needed to build a project with an underlying mission to work toward, cultivate, and advance equity and social justice.

Core Principles

Equity and social justice inform the core principles of community-engaged research. The spectrum of approaches under the umbrella of community-engaged research should include some version of all core principles. Core principles can be summarized into three themes: (1) partnership and process, (2) knowledge and epistemology, and (3) power and structure (Haapanen & Christens, 2021).

Partnerships and processes refer to the degree of engagement and collaboration with the community and the specific processes adopted to facilitate collaboration. Partnerships in community-engaged research typically refer to academic researchers partnering with some combination of community residents, providers, organizations, government officials, or other stakeholders to carry out research. These partnerships are also referred to as community-academic partnerships. Academic partners may be part of the community in some capacity or an outsider. Given people often participate in research, *how* people partner is a critical factor, although not the only factor, that distinguishes community-engaged research from other forms of research where community members are largely study participants, not collaborators. Within community-engaged research, the types of collaboration (e.g., consultation, leading) may vary across different approaches (discussed in Chapter 3) but all partnerships should be meaningful and genuine (Wallerstein & Duran, 2010). Processes to support the partnership

include co-learning and co-creating (Haapanen & Christens, 2021). Co-learning harnesses bidirectional understanding of the academic partner's skill sets, strengths, and resources and the community's strengths, resources, and needs while building trust and commitment to partnership. Cocreating research can happen to varying degrees, from identifying the research question collaboratively to codeveloping each aspect of the research collectively. Existing resources like the *Guiding Principles of Partnership* developed by the Community-Campus Partnership for Health (2013) are ideal to assist in starting discussions around what is needed to build and nurture partnerships. Strategies to help facilitate healthy collaborations and build partnerships are discussed in detail in Chapter 4.

The second bucket of principles for community-engaged research is knowledge and epistemology. Many academic researchers are trained to perceive that knowledge can only be constructed through research conducted by trained experts who hold advanced degrees in their disciplines. In traditional research, the researchers are viewed and treated as the sole experts who are expected to engage in researcher-led approaches to produce knowledge. Knowledge production, however, can and does exist outside of research and through lived experience. Community-engaged research assumes that researchers and community members are both experts who can learn from one another. Expertise is not limited to researchers; community members hold unparalleled expertise uniquely derived from lived experience and practice wisdom. Community-engaged research deliberately integrates the expertise that the local community holds with academic research partners' expertise for mutual learning within and between the community and researchers. Knowledge creation occurs collaboratively between researchers and the community.

In practice, this translates to academic partners recognizing the expertise of community partners and their ability to identify strategies and solutions that are the best fit for their community. Using a strengths-based lens is central as it views people as experts in their own lives and identifies community strengths and resources as essential features of the change process (Caiels et al., 2021; Israel et al., 2008). Doing research *with* communities and not *on* or *for* a community can disrupt hierarchies that place all the power with academics as the only creators of new knowledge (Haapanen & Christens, 2021). When done well, community-engaged research includes not only distinct and diverse groups of individuals from the community but also includes differing perspectives which enhances opportunities for "co-learning" or "mutual learning" and facilitates the cocreation of knowledge. The value of community-engaged research is not restricted to the research outcomes, as with other traditional research approaches. The cocreation of knowledge in community-engaged research is about the quality of the process (Nicholas et al., 2019) and using processes that entail reciprocated dialogues and power sharing (Zurbriggen & Lago, 2019).

Power sharing and a shared power structure make up the third bucket of core principles in community-engaged research. Sharing power minimizes power imbalances and manages hierarchical power dynamics between the community and academic partners. Power sharing allows for reciprocity in information and expertise, for the cocreation of knowledge. Through power sharing and the cocreation of knowledge between researchers and community members, community-engaged research provides a better understanding of inequities and functions as collaborative advocacy for fairness and more equitable circumstances. Sharing power and

leading research together "contributes *directly* to the flourishing of human persons, their communities, and the ecosystems of which they are part" (Reason & Torbert, 2001, p. 6). Within community-engaged research, some attempt to alter power structures is needed that expand, create, or identify alternative structures that promote equity.

Sharing power and leading research together "contributes *directly* to the flourishing of human persons, their communities, and the ecosystems of which they are part" (Reason & Torbert, 2001, p. 6).

Although the partnership and rapport built through collaboration is an important core principle, Oetzel and colleagues (2022) identified structural governance and partner commitment to community-engaged research as two of the most important elements for success. They defined ***structural governance*** as the processes used for approvals, joint decision making, and transparency and sharing of the project budget. **Partner commitment** reflects commitment to community-engaged research principles, the "fit" of the partnership, and space for critical reflection. Both structural governance and commitment to principles directly facilitate power sharing, transparency, and equity in the research process. Although the study conducted by Oetzel and colleagues (2022) focused on CBPR, these core principles translate to community-engaged research more broadly. All things considered, equitable partnerships, healthy collaborations, cocreating knowledge, as well as shared power structures all facilitate the underlying missions of promoting equity and social justice—not only in research outcomes but also in research practices (Haapanen & Christens, 2021).

APPLYING COMMUNITY-ENGAGED RESEARCH

Community-engaged research is not a one-size-fits-all approach, meaning that it will look different from one community to another. Each community is unique in their needs, how much they want to collaborate, how much time and space they can devote to collaboration, and the ways they want to participate. One example of community-engaged research should not be expected to work in the same way or have the same impact for another community. Each community is distinct, with various characteristics that form the whole. Thus, the development of community-engaged research must be tailored to the specific communities involved in the research. When research development is not tailored to specific communities, it runs the risk of imposing research practices that are not aligned with the underlying principles of community-engaged research and may ultimately cause harm or further marginalize communities. There is only one strategy that holds true across all community-engaged projects when academic partners are initiating the work—identify the right approach *with* the community partners.

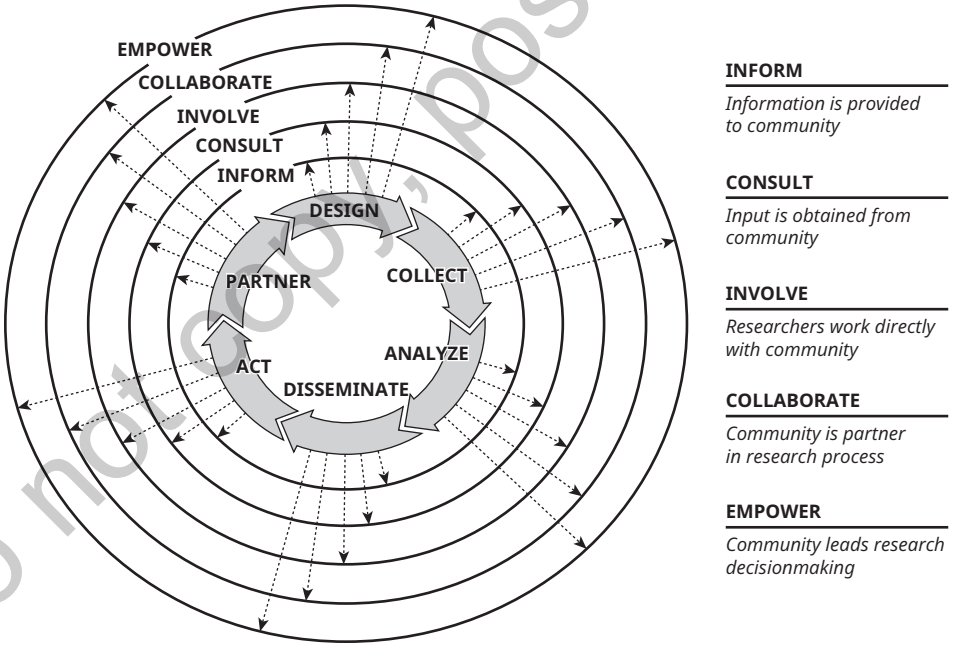
Several questions may arise when collaborating with marginalized communities on community-engaged research. One common question is this: Given the complex power structures in society, how can the community and academic partners create an equitable partnership

in the execution of a community-engaged research project? When conducting research with marginalized populations, it is particularly important to understand and account for the various forms of marginalization that reinforce unequal power dynamics in society (Velarde et al., 2021). Much of the focus of power sharing as an underlying principle of community-engaged research is directed to the research processes, but power sharing should also be the goal within proposed actions. Community-engaged research prioritizes the use of approaches to promote social justice and fairness, through shared values between the community and the academic partners in addressing social inequities. Therefore, proposed actions must consist of shared values between the community and academic partners and be aligned with social justice. This highlights the importance of working *with* the community to design the approach, reiterating the belief system of "nothing about us without us" to highlight the community expertise in the research topic and the community's power within community-engaged research partnerships.

Still, community engagement is not one-size-fits-all. Vaughn and Jacquez (2020) provide one example of the different points of engagement throughout the research process (see Figure 2.1). Collaborative and shared decisions should be made at each of these points to

FIGURE 2.1 ■ Participant Choice Points in the Research Process

At each step in the research process, there is a choice about the degree of participation. The choice guides the selection of research methods and tools.



Note. Levels of participation based on Spectrum of Public Participation. From "Participatory Research Methods – Choice Points in the Research Process" by L. M. Vaughn and F. Jacquez, published in 2020 in *Journal of Participatory Research Methods, 1*(1), https://doi.org/10.35844/001c.13244. Licensed under CC BY 4.0, Creative Commons License CC BY 4.0, https://creativecommons.org/licenses/by/4.0/.

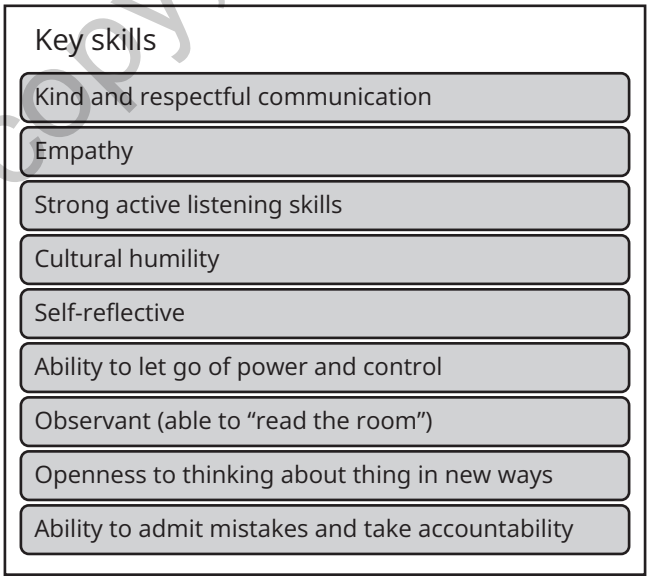
determine the level of participation that community members want. Each of these decisions informs the community-engaged research approach that will be used. On the other hand, some teams may decide on the specific community-engaged research approach that they want to use at the onset and work collaboratively to determine how that approach will be applied. As such, there is no consensus within community-engaged research about the "best" approach for community engagement, as this differs from one community to another and will look differently across research endeavors.

PREPARING FOR THE RESEARCH

Academic researchers can be most successful engaging in community-engaged research after they have done the work that is needed to learn about and recognize the current and historical oppression that marginalized communities face. For some researchers, they have lived these experiences and understand oppression firsthand. For others, this is not a lived experience so intentional and thoughtful learning is needed.

As depicted in Figure 2.2, numerous interpersonal and communication skills facilitate thoughtful learning, building rapport with new community partners, and maintaining strong partnerships over time. Communication skills, in general, are essential. Understanding customs and traditions around communication is important to ensure respectful and kind engagement. As an example, an academic researcher may be accustomed to starting meetings and jumping right into the agenda. This may be off-putting in communities where there is a period of greeting people, saying hello, and catching up before the meeting begins. Part of

FIGURE 2.2 ■ Key Skills for Successful Community-Engaged Research



good communication includes active listening and nonverbal skills (e.g., culturally appropriate eye contact). The best way to learn about traditions, customs, and social norms in new communities is to be present, listen attentively, and observe. Cultural humility is essential in this process. Cultural humility includes critical self-reflection on your own history, beliefs, and social position while being open and appreciative of differences to one's own culture (CDC, 2022). The Centers for Disease Control and Prevention (CDC; 2022) offer the following guidance for global public health professionals that promotes cultural humility: "Avoid the posture, framing, and language of hierarchy, patriarchy, supremacy, saviorism, and colonialism." Finally, empathy, or "the act of perceiving, understanding, experiencing, and responding to the emotional state and ideas of another person" (Barker, 2008, p. 141), may not sound like a typical skill needed in research. However, empathy helps to form relationships and facilitates compassion and humility. It helps to see ideas and challenges from another perspective and can lead to stronger partnerships.

It is also important for academic researchers to be able to let go of and share control of the research process. Academic researchers may instinctually dictate how the research should happen. As these instincts surface, it is important to be aware of them and then work to challenge them. Creating space for people to talk, think, and explore is essential. Is the academic research partner talking more than community research partners? If so, why and who is not talking during these times? Reflection and observation are needed to disrupt traditional approaches. If academic researchers find themselves slipping into positions of power or authority, there are opportunities to recover from these potential ruptures. Academic researchers taking part in community-engaged research must be able to admit mistakes and take accountability. Mistakes will happen so having the right mindset and toolkit to address these mistakes is an important part of preparing to do this work.

Finally, academic researchers will also need to be prepared to challenge institutional practices that undermine the principles of community-engaged research. For example, university polices around financial compensation or hiring practices, transparency and negotiation of funding including requirements around indirect rates (i.e., facilities and administrative fees), fiscal management and reporting standards, and institutional review board flexibility with amendments to protocols may need to be challenged to ensure equitable partnerships and shared power (Hallmark et al., 2023). In addition, academic researchers will also need to develop strategies to manage their institution's expectations around publishing for promotion and tenure. Community-engaged research is time consuming, and key publications that benefit the community (e.g., short reports in magazines or online newsletters) are often not the same publications that the academy recognizes for promotion (i.e., peer-reviewed publications; Peters, 2023). Academic researchers should be mindful of these pressures, develop a plan (e.g., conduct a systematic review of literature as a separate line of research), and advocate for expanded definitions of research impact (see Peters, 2023) regardless of whether the researcher is currently engaged in community-partnered research. Having a plan in place will keep academic research partners accountable to community research partners while also challenging those institutional practices that may cause undue pressure and undermine community-engaged research core principles.

CONCLUSION

Given that traditional research training has a narrow view of the ways knowledge is created, it is also important for academic researchers to examine their own personal epistemology. If an academic researcher does not truly believe in the mission of this work or have trust in the core principles as facilitators of knowledge building, this is not the right research approach to use. Unexamined bias and beliefs in positivist science can hamper the research process and cause further harm to communities at the hands of research. In the next chapter, we review the umbrella of community-engaged research approaches that researchers should consider once they have examined their own personal epistemology and determined they are ready to actively participate in community-engaged research.

REFLECTION QUESTIONS

1. Thinking about your specific areas of interest in research, what are some possible ways that you might define *community*?
2. As you learn about the core principles of community-engaged research, what personal or professional challenges do you envision?
3. What kind of strategies or resources will you use to overcome those challenges?

KEY TERMS

academic partners
community
community-engaged research
equality
equity
partner commitment
social inequities
social justice
structural governance